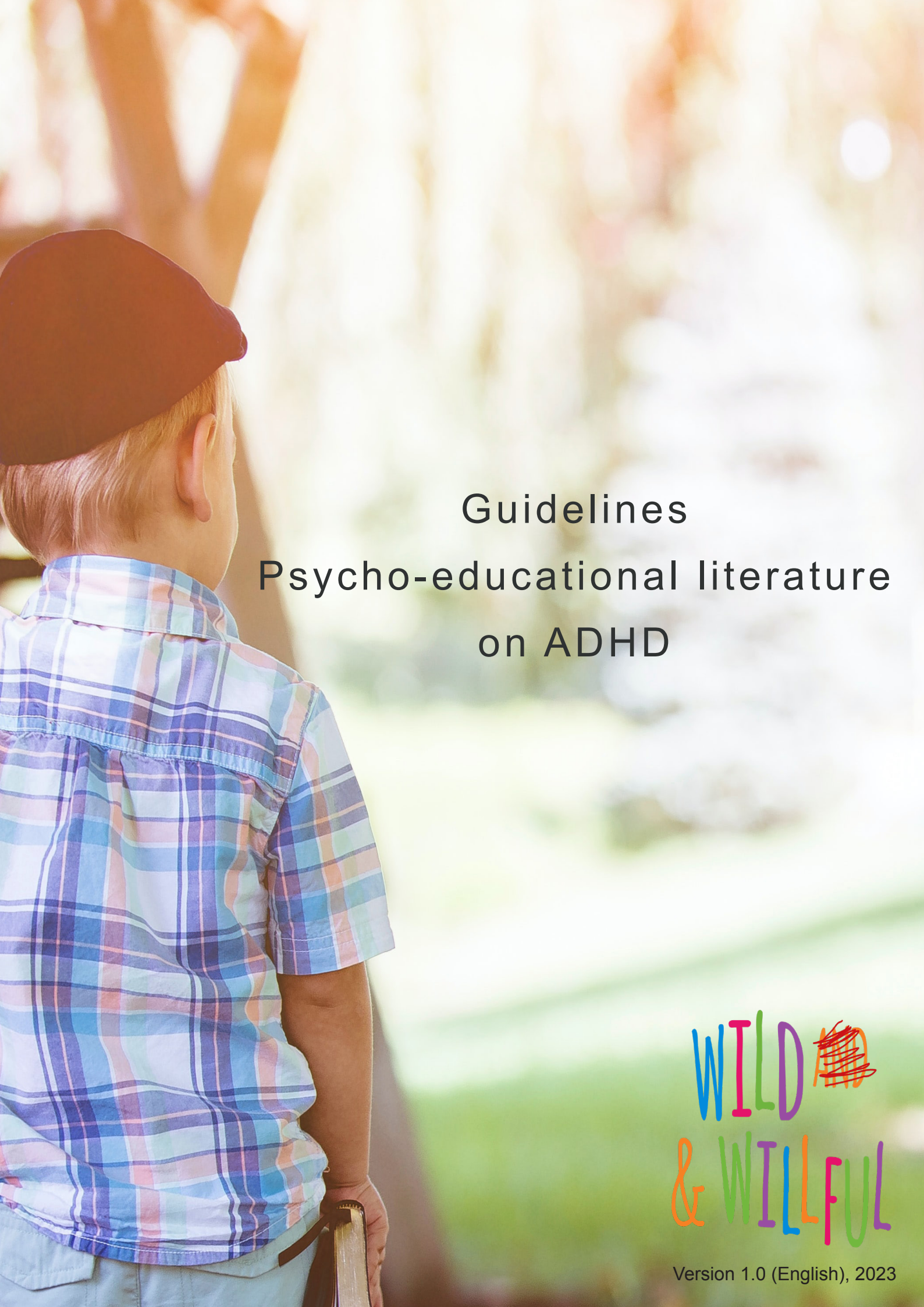

Guidelines
Psycho-educational literature on ADHD

WILD & WILLFUL

Version 1.0 (English), 2023

Summary

ADHD is a descriptive classification that describes behavior. The behaviors that may lead to this classification have different motives and causes. We therefore describe ADHD as ‘multifactorial’, because different factors, both dispositional and environmental, are related in differing ways; the ‘mix’ of factors is different for each individual who displays these behaviors. Although in the past decennia the biomedical view on ADHD was dominant, there is increasing attention to environmental factors and societal norms and contexts – why are certain behaviors experienced as negative or disordered? Despite this, multi-faceted view, descriptions of ADHD in psycho-educational literature on ADHD are often one-sided or confusing. This set of guidelines gives suggestions for a clear explanation of ADHD. It is a translation of guidelines on this subject published in the Netherlands in 2021.

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Contents

Reading guide

These guidelines are intended for care-professionals who write about ADHD on, for instance, websites, in brochures or books. These guidelines may be useful as a foundation for psychiatrists, psychologists, social workers, etcetera, who explain to parents and children what ADHD is and what it is not, what we do know, and do not know based on research. Additionally, this document can also be of great interest to those who have some prior knowledge about restless, unruly, impulsive or inattentive behavior and ADHD and who want to improve their understanding of how research in this domain can best be interpreted. Last but not least, journalists who write about ADHD are advised to study these guidelines.

Some information can be complicated, even for healthcare professionals/journalists with a scientific background. Some passages that primarily serve as background information are indicated with ⓘ. Despite the careful crafting of this text, it is possible that some information is missing or needs to be improved. It is highly appreciated if you contact us about with questions or suggestions for improvements. Via s.te.meerman@rug.nl or l.batstra@rug.nl you can get in touch with us.

Introduction

ADHD is a descriptive classification that describes behavior. ADHD is defined in the Diagnostic Statistical Manual of Mental Disorders, currently in its fifth edition (see Appendix A). The behaviors that may lead to this classification have different motives and causes. We therefore describe ADHD as 'multifactorial', because different factors, both dispositional and environmental, are related in differing ways; the 'mix' of factors is different for each individual who displays these behaviors. Although in the past decennia the biomedical view on ADHD was dominant, (in the Netherlands) there is increasing attention to environmental factors and societal norms and contexts – why are certain behaviors experienced as negative or disordered in the first place?[1] Despite this multi-faceted view, descriptions of ADHD in psycho-educational literature on ADHD are often one-sided or confusing[2,3,4]. Therefore, it is very challenging to communicate the outcomes of ADHD-related research to the general public. In particular, it is difficult to explain that group outcomes are often very limited in making predictions about individuals who meet the ADHD criteria. This poses a challenge to communicate information clearly, especially for those without a scientific background. Further, what does it mean when the outcome of research is 'statistically significant'? Do children with an ADHD-classification have different genes? These guidelines answer such questions and aim to facilitate communication on the outcomes of ADHD studies amongst professionals and lay-people.

The guidelines are primarily based on examples taken from academic textbooks as well as websites addressed to the general public. First, examples are discussed which are likely to confuse readers or may give a distorted view of that ADHD 'is'. The examples do not necessarily suggest that the authors lack understanding of the research they describe. However, confusion can arise because the authors may assume the readers have prior knowledge that they may in fact not have.

To clarify what are considered more desirable forms of descriptions in psycho-educational literature, such examples, again from both textbooks and the internet, are also presented and compared to the examples that are deemed of lesser quality. In (rare) cases where there were no clear examples present, the taskforce has constructed such an example, often compiled with information from existing examples.

In the first place this document is concerned with scientific research surrounding the reasons for, and causes of, restless, impulsive, inattentive behaviors. The assumption is that for effective support and care, or for the necessary (societal) contextual adjustments, a thorough understanding of backgrounds and course of such behavioral problems as well as problematic contexts is the starting point. Chapter 1 of this document discusses ADHD and brain studies. Chapter 2 discusses ADHD and environmental influences and Chapter 3 discusses ADHD and genetics. In Chapter 4, several more common challenges when presenting research results are discussed in more detail. Finally, Chapter 5 discusses several choices that need to be made for reporting about ADHD in psycho-educational literature. In the appendices the references used and some background information about this document can be found.

Chapter 1: ADHD and the brain

In this chapter, we discuss psycho-educational literature on brain-size/anatomy and brain activity of groups of children/adults meeting the ADHD criteria in comparison to 'controls' (groups of people without an ADHD-classification). This research is mostly concerned with understanding the backgrounds of impulsive behaviors and inattentiveness. Unfortunately, both the explanation, and as a result, the interpretation of such studies is problematic. Important issues/points of consideration are:

Interpretation of research

- Research often examines the existence of an **average difference** between a research group and a control-group. For instance, researchers compare the average brain-size of a group of people with an ADHD-classification with a control-group; of individuals without such a classification. When there is less than 5% chance that the average difference found between the case- and control-group is coincidental, it is called '**statistically significant**'. This does not mean the difference is useful in daily practice, or '**clinically relevant**'. This depends, amongst others, on 'effect size': how big or small is the difference in, for example, average brain size? The average differences in brain-anatomy/physiology and –chemistry found thus far, although 'statistically significant' are not useful in daily practice; they are not clinically relevant. Beware however, with 'big' or 'small' differences does not mean big/small in terms of, for example, volume. Big/small difference in effect size refers to: how much overlap is there between the case and the control group? This means that if, for example, in the case group (those with an ADHD classification) a certain area of the brain is smaller, on average, the effect is considered small if there are also many people in the control group in which this area of the brain is smaller. If, on the other hand, this smaller area of the brain is quite unique for those in the case group, and this are of the brain is only smaller in relatively few people in the control group, this is called a 'large effect size'. In ADHD, as a rule, brain studies only display very small effect sizes: there is a lot of overlap between the case and the control group, and this is why brain tests are not possible (and the differences are not 'clinically relevant').

- **Correlation** is not the same as **causality**. One attribute, such as brain size, does not necessarily cause (restless, inattentive) behaviors. Brain 'plasticity' means the brains develop in relation with the environment. For example, studies of musicians' brains show that areas of the brain associated with 'fine motor skills' are larger on average; differences that are most likely acquired. Brain structure has not caused the behavior (being able to play an instrument well) but the behavior –a lot of practice- has most likely influenced the brain development and structure.

- It is also important to consider the (often limited) representativity of the **case- and control groups**. The group of children that researchers select for the 'case' group often display the restless/inattentive behaviors of the ADHD criteria in a relatively severe manner. At the same time, those children that researchers select for the control group are often wat could be called 'hypernormal'. Often, these children are selected because they themselves, nor their family of birth or the secondary family have used psychologic/psychiatric services, while in society at large many people or family members have received such services at some point in their life. Results of studies with these relatively extreme samples can therefore not automatically be transferred to other groups and individuals with/without an ADHD classification.

The examples displayed below clarify that it can be a challenge to write clearly about the outcomes of group studies, possibly because some prior knowledge is assumed that the reader does not always have[5]. The reader can interpret small effect sizes as absolute or get the impression that there is a causal connection while only a correlation is established. Or, the reader can think that when an average difference is established between case- and control group, this implies that this applies to all children. We discuss several desirable and less desirable ways of describing the outcomes of studies of neuro-anatomy, -physiology and –chemistry.

Anatomy

The next example can be confusing for readers:

Example 1: less desirable

"In children with ADHD, there is a general reduction of volume in certain brain structures, with a proportionally greater decrease in the volume in the left-sided prefrontal cortex." [6]

This example does not mention that researchgroups overlap with controlgroups. Many children with an ADHD-classification do not have a general reduction of volume in certain brain structures, or any decrease in the volume in the left-sided prefrontal cortex. Research indicates[7] that readers may get the impression that all people with an ADHD-classification have different brains[8] ⓘ. The next example is clearer in this respect.

Example 2: more desirable

"When groups of children with ADHD are compared to groups of children without ADHD, there are performance differences in computertasks and measurements of higher cognitive functions, brain scans and genetic make-up (…). However, there are different anomalies in different children with ADHD, and there are consistently children with ADHD that do not deviate from other children. It is not possible to diagnose ADHD in this fashion, and for diagnoses we depend on observable behavior as defined in the DSM-IV-TR9.[9]

This passage clarifies that children who meet the ADHD criteria do not necessarily have, (amongst others) smaller areas of the brain. In logical terms, smaller brains are not a 'necessary condition'. The next passage emphasizes that when someone does have a smaller brain area, this does not mean he/she has ADHD. So, in logical terms, smaller brain areas are not 'sufficient' either.

ⓘ The erroneous suggestion that average group outcomes, such as smaller brain size in a group of people who meet the criteria for ADHD apply to everyone in the group is known as 'the ecological fallacy[8]. Group outcomes predict very little about individuals in the group.

Example 3: more desirable

> ***"… non-diagnosed, typically developing youths exhibited brain changes similar to youths with the syndrome of ADHD...."*** [10]

Examples 2 and 3 combined clarify that smaller brains are not a necessary (example 2) nor a sufficient condition (example 3) for ADHD. These examples combined explain why it is not possible to see different brains in those who meet the criteria for ADHD: if a 'change' is found at all, it might not explain the behaviors since 'normal' children can have these 'changes' as well.

For comparison: parental divorce is also a risk factor for ADHD, though of course not every child with an ADHD classification has experienced a divorce – it is not a necessary condition. At the same time, divorce does not always lead to ADHD. It is not a sufficient condition either. In general, this applies to almost all disorders defined in the Diagnostic Statistical Manual.

Persistence and anatomy

Research has shown that the small average differences in brain-anatomy between groups of those with and without an ADHD classification are not permanent or persistent. A large meta-analysis from 2017 [11] shows there are no statistically significant differences in brains of adults with an ADHD classification compared to control groups. Often, this finding is not mentioned as in the example below.

Example 4: less desirable

> ***"…reduced brain volume has been revealed for several brain structures, with reductions in total volume estimated at 3 to 5%."*** [12]

A simple addition as the one below can explain that a low brain volume is not necessarily persistent.

Example 5:

> ***"Ultimately, the growth of the brains of the children with ADHD caught up with those of unaffected children."*** [13]

We emphasize that these outcomes are also based on group studies. Some children with an ADHD classification retain smaller areas of the brain, just like some children without an ADHD classification. In both groups, parts of the brains can also become larger than average.

"Normal" brain development

Finally, it is considered undesirable to make 'normative' claims about ADHD and brain-anatomy. This means that claims about which brain-anatomical features are considered (ab)normal are preferably avoided. Research can determine group differences but cannot determine which trajectory of brain development is better. For instance, on average, men also have larger brains than women. Again this does not mean all men have larger brains and it certainly does not mean that women have a brain developmental disorder. Theoretically smaller brains could be more efficient. Additionally, compared to women's smaller average height, their brains are not smaller. However, the next quote suggests that *differences* in group averages imply brain-related *problems*.

Example 6: Less desirable.

> ***"In general, researchers now assume that these active, restless children suffer from a disorder in the development of the central nervous system."*** [14]

A slower than average brain disorder does not imply a brain disorder.

Then next example discusses the slower than average brain development while avoiding the above mentioned flaws like suggesting that faster brain developmental is better. At the same time, the example clarifies the overlap between the research groups and the absence of anatomical differences in adult research samples.

Example 7: more desirable

"the development of the brain, that can be slower in some children who meet the criteria for ADHD, has –in general- caught up by the times these children reach adulthood. Not every child with ADHD catches up, but the same is true for children without an ADHD classification: they can have similar lag in growth that does not completely catch up in adulthood and in both groups it does not necessarily affect behavior in a negative way as brains simply differ from one person to the next." (example by taskforce).

Table 1: base-ingredients for desirable education on Brain anatomy:

	Less desirable	More desirable
Necessary and sufficient	Suggesting all those with ADHD have smaller brains (ex. 1,2)	Emphasizing there is no consistent relation between brain anatomy and ADHD (ex. 3 & 4)
Non-persistence of brain-growth	Not mentioning that slower than average brain development is not necessarily permanent. (ex. 1 & 6)	Emphasizing that brain development varies and in ADHD it is only slower than average during childhood in some children; emphasizing brain development is variable from one person to the next (ex. 5)
Normative claims	Suggesting that brain development that is not average implies disorder or illness (ex. 6)	Emphasizing that differences in brain development or shape does not necessarily imply a disorder or hampered brain development (ex. 7)

ADHD and neurochemistry/physiology

Besides brain-anatomy, brain research on ADHD also includes the study of brain activity (physiology) and the presence of certain substances, such as neurotransmitters (signaling substances) in the brain: the study of neurochemistry. A well-known neurotransmitter for example, is dopamine. In this type of research subjects typically perform certain tasks, while researchers examine, for instance, brain activity. Research into neurophysiology and chemistry has many similarities with research on neuroanatomy. Again, groups of children with an ADHD classification are often compared with control groups, using techniques such as magnetic resonance imaging (MRI).

The outcomes of studies of neurophysiology and neurochemistry also show many similarities with studies of anatomy. Again at the group level, small mean differences are found but again there is much overlap between the research groups. So again, no unique brain characteristic is found, i.e. no particular blood flow or a neurotransmitter present to a greater or lesser degree that can predict whether a person will meet the behavioral criteria for ADHD. An additional problem relative to brain-anatomy research is that brain physiology and -chemistry are much more variable. Blood flow while doing a particular task may be be lower/higher at one time than at another time of measurement. Also, with respect to blood flow or the amount of neurotransmitters available in the brain there are no known "calibration values" that can be considered normal or abnormal. It is important to communicate this in education literature, and therefore the following excerpt is considered less desirable.

Example 1: Less desirable

> ***"In a healthy brain, concentration causes blood flow to increase appropriately in certain regions, especially the prefrontal cortex. This helps us to focus, plan ahead, stay organized, and follow through on tasks. However, when people with ADD/ADHD try to concentrate, blood flow decreases in the prefrontal cortex, making it more difficult for them to focus and filter out distractions. In fact, the harder they try to concentrate, the harder it can get."*** [15]

This excerpt does not mention that these are group findings, and this omission suggests 'dysfunction' in anyone with an ADHD classification. There is also no basis for the claim that blood flow to the prefrontal cortex actually decreases. Furthermore, in this excerpt it is suggested that there is clarity about the distinction between normal and abnormal functioning. However, there are no known calibration values about what, for example, constitutes an (ab) normal amount of blood flow[16]. Partly because none of the values found for variables like blood flow only occur in people with ADHD, it is difficult to say what can be considered a normal/abnormal value. And vice versa, in many people with ADHD there is no higher/lower than average bloodflow. The following excerpt is more desirable.

Example 2: More desirable

> ***"ADHD is probably not a single neurobiological entity, but rather an umbrella term covering a variety of pathophysiological profiles. Each deficit (...) affects only a minority of cases."*** [17]

This example clarifies that there are no biological differences that apply to the ADHD group as a whole, as differences may affect the behavior of only a minority of the group.

Nevertheless, this excerpt is equally normative as it speaks of a 'deficit'. The following excerpt omits normatively charged jargon and is therefore preferable.

Example 3: more desirable

> ***"… when performing more complex tasks, children with ADHD use brain regions associated with more basic (motor, visual and spatial) processes, whereas children without ADHD are inclined to use brain regions associated with the planning and organization of behavior, i.e. the higher cognitive functions."*** [18]

The authors avoid the suggestion that the tendency to use certain brain areas is better or worse than other areas. The authors also partly avoid generalization. They write that children without ADHD are 'inclined' to use other brain areas; thus, this does not apply for all children. However, some information is still missing. For example, children with ADHD do not always, but at best 'more often', use brain areas associated with more basic processes. Also, it would be good to clarify that children without an ADHD classification use these brain areas in complex tasks. A better example would be the following.

Example 4: most desirable

> ***"Groups of children who meet the ADHD criteria, when performing more complex tasks are, on average, slightly more likely to use brain regions associated with more basic (motor, visual and spatial) processes, whereas groups of children without ADHD are on average more likely to use brain regions mostly associated with the planning and organization of behavior, i.e. the higher cognitive functions" (example taskforce).***

Neurochemistry and medication

Research on neurochemistry is frequently associated with the effects of medication. Because we are in fact unable to measure concentrations of neurotransmitters such as dopamine and norepinephrine directly, we look at the amount of receptors for these substances in the brain. There is evidence that adults with an ADHD classification on average have more of these receptors and the assumption is that as a result there is less available dopamine and/or norepinephrine in the brain. Active substances in medications, such as methylphenidate, make these substances available longer. Psycho-educational literature can be unclear on such matters, as in the following example:

Example 5: Less desirable

> ***"ADHD is a neurobiological disorder. Something is not going well in the brain; there is deficient in so-called neurotransmitters (dopamine and norepinephrine). These neurotransmitters ensure that information between one nerve cell is passed quickly and properly passed on to another nerve cell. Because of the deficiency, that process does not go well or does not go fast enough, with all the consequences that entails."*** [19]

Firstly, this excerpt generalizes: the results are again at the group level so at the individual level it is not clear whether there is an alleged 'deficit'. Additionally, the normative aspect is not desirable: there are no known values of dopamine or norepinephrine that are too high or too low. Furthermore, these kinds of values are not known for children. For ethical reasons, PET scans have not been used to study the amount of receptors in the brain of children. If the assumption is at all correct that the presence of more receptors means less dopamine is present in the brain, we thus do not know if this is also the case in children. The following example is more critical of some of the aspects mentioned above and is therefore more desirable.

Example 6: Desirable

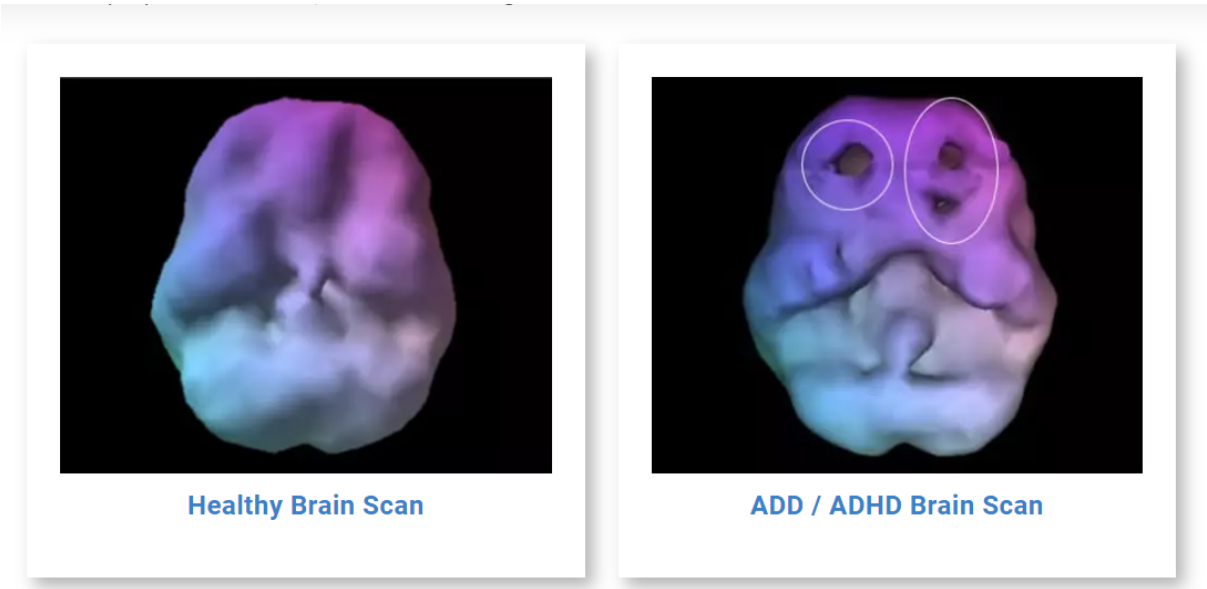
> ***"… it would behoove us in the scientific community to avoid describing findings as "abnormal" (i.e., abnormal blood flow, abnormal circuitry, abnormal connectivity, abnormal activation) and instead to use more accurate descriptive terms such as "statistically less activity" or "statistically less glucose metabolism" or "different" when comparing neuroimaging findings between participants with ADHD and control subjects.***[20]

In this statement, normative statements are avoided, and with the suffix 'statistical' it is clearer, at least to many scientists, that these are group findings. In information for laymen this will have to be described in a more accessible way, and with regard to research on children, there remains limitation that less is known about neurochemistry.

The use of images

(Public) information about ADHD and brain research regularly uses images of brain scans. This can help to clarify at what locations in the brain average differences in structure, activity or (assumed) levels of a particular neurotransmitter have been found. However, regularly, images are used of individuals from the research or control group that are not necessarily representative of the average difference. Instead, it often involves a more extreme example from both the study and control group. In addition, it is then suggested, for example in the accompanying text, that each person from the research group shows such a pattern, as in the following example:

Example 7: Less desirable:

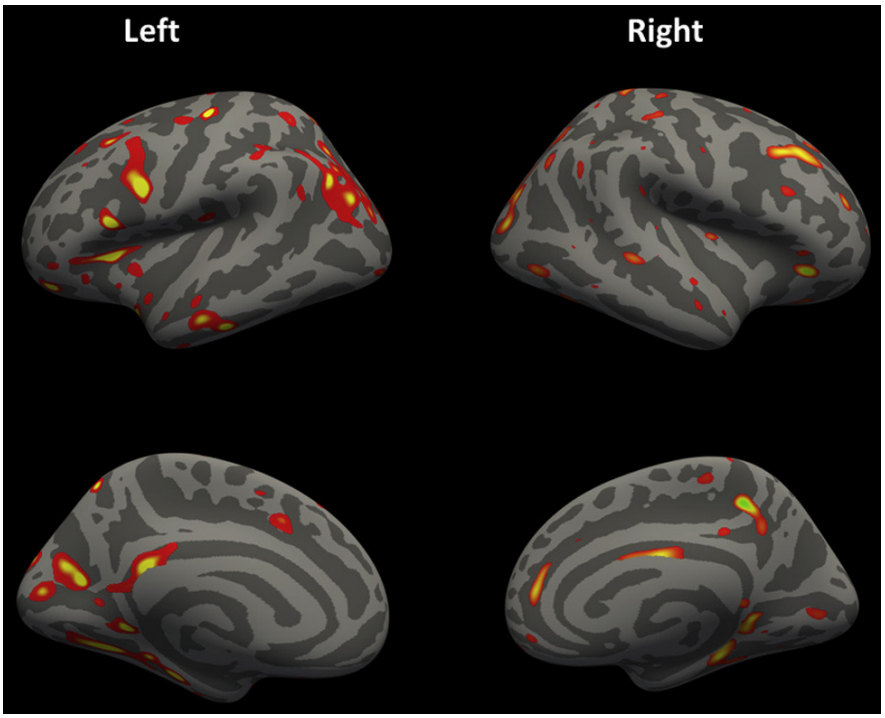


"Spect (Single photon emission computed tomography) is a nuclear medicine study that evaluates blood flow and activity in the brain. Basically, it shows three things: healthy activity (blood flow) too little activity, or too much activity. The healthy surface brain SPECT scan on the left show full, even symmetrical activity. The ADD/ADHD scan on the right, taken during a concentration task, reveals decreased blood flow (the areas that look like "holes") in the prefrontal cortex."

The caption, by generalizing group averages to individuals, further contributes to Possible misunderstandings and misinterpretation of such scans as there is no pattern of activity unique for those with an ADHD classification. The excerpt is also highly normative, suggesting 'healthy activity (blood flow) too little activity, too much activity'. To avoid being normative and avoid the suggestion that this pattern of brain activation is unique to everyone in the group with an ADHD classification, it is preferable to speak of group differences in which the pictures can serve to make clear where the group differences occur. The following example is therefore more desirable, and fortunately much more common:

Example 8: More desirable

> ***"Brain areas for which smaller volumes were found in the groups with ADHD, with or without ODD, relative to the control group, based on whole-brain analysis (not corrected for multiple comparisons; p < 0.0001)"***



"Colored areas: significant group differences; yellow color: center of area; darker areas: sulci; lighter areas: gyri [22]

This example is preferable because it speaks of *significant group differences*.

Table 2: base-ingredients for desirable education on neuro-physiology, -chemistry.

	Less desirable	More desirable
Necessary and sufficient condition	Suggesting that all children with ADHD have higher or lower activity or presence of certain neurotransmitters in the brain (ex. 1)	Making it clear that children with ADHD do not necessarily have a higher or lower activity or presence of certain neurotransmitters in the brain, and that these are very small differences at the group level are concerned (Ex. 4)
Variability of brain activity and/or neurotransmitters present	Leaving unmentioned that there is no permanent value of for example, the presence of neurotransmitters and/or brain activity (ex.1, 5)	Making it clear that brain activity and the presence of neurotransmitters not only varies within the group, but also varies greatly within the individual from moment to moment (Ex. 6)
Normative claims	Normatively charged jargon that suggests that there are certain values of brain activity or the presence of neurotransmitters that are 'too high' or 'too low' (ex. 5)	Speaking of differences rather than 'dysfunction' or 'deficiency' and making it clear that no certain desirable values are known (e.g. 3, 6)
Careful use of illustrations	Suggesting that scans of individuals apply to everyone in the control/research group (ex. 7)	Use illustrations explicitly to explain that the differences found apply only at the group level and have little predictive value for individuals (ex. 8)

Chapter 2: ADHD and environmental influences

For clear writing on environmental influences on ADHD, the same principles apply as for neuroanatomy, physiology and chemistry. Generalizations should be avoided and clarity about the interpretation and limitations of the research are just as important here. In existing educational literature, it is actually difficult to find less desirable examples about the influence of environment. A statement such as *persons with ADHD have less money or suffer from poverty* has fortunately not been encountered by the taskforce, unlike statements such as *persons with ADHD have smaller/differently functioning brains*. This is interesting, considering that poverty and social deprivation have a stronger connection to ADHD than brain attributes[23,24] When describing environmental influences, ifs and buts are more frequently made. Still, in this context there is also room for improvement.

Example 1: Less desirable

> ***"....no attention to other possible causes of ADHD such as poverty, overburdened parents and teachers, and the performance society."*** [25]

Although it is important that factors such as poverty receive attention, this passage could be improved because it suggests that said factors have a direct causal relationship with ADHD. If there is a correlation between two variables (for example, poverty and ADHD), it does not necessarily follow that one causes the other cause. A third variable or a combination of other variables can also cause the two variables to show a correlation. In the case of poverty in relation to ADHD, this may include unstable family circumstances, domestic violence, attachment problems, that may be the root cause rather than poverty per se.

Example 2: More desirable

> ***"Adverse social and family environments such as low parental education, social class, poverty, bullying/peer victimisation, negative parenting, maltreatment and family discord are associated with ADHD. However, the designs used so far have not been able to show that these are definite causes of ADHD."*** [26]

As this passage notes, the research designs that have been used to date cannot yet be conclusive about causality. It is also important to consider that overarching concepts such as poverty can be examined in different ways. For example, neighborhood in which one lives, housing, available monetary means for sport and other activities, etcetera, could exert influence. Thereby, poverty may itself have other causes in the social domain but may also have to do with individual capabilities.

Although seeing factors as poverty in perspective is important, the taskforce does note that environmental problems are regularly downplayed alongside an emphasis on biological influences as demonstrated in the following example.

Example 3: Less desirable

> ***"... children with ADHD are more likely to come from homes in which marriages are unhappy and family stress is high. But a stressful home life rarely causes ADHD. Rather, these children's behavior can contribute to family problems, which intensifies the child's pre-existing problems."*** [27]

In this excerpt, the associations that exist with social deprivation and the possible underlying causal links are almost entirely set aside and child behavior is presented as the basis of the problems. Although children's behavior may contribute to family problems, this excerpt hardly does justice to the multifactorial view where different causes interact. The next example also somewhat downplays the links to environmental influences, but is more nuanced.

Example 4: More desirable

> ***"Environmental factors relate to birth, prenatal exposure to nicotine and alcohol, environmental toxins, sensitivity to certain color and nutrients and the psychosocial influence of upbringing and family. To think low socioeconomic status and/or pathology present in the educators, such as depression, alcoholism and antisocial behavior, issues that can increase the individual vulnerability may increase. These risk factors are based on correlational research - indicating that there is some relationship - but this says nothing about causation."*** [28]

It should be noted, however, that a link or correlation may not necessarily imply causation, but correlation is a prerequisite for causation and thus may well indicate that one thing partly causes the other. Correlation and causation are discussed in the beginning and of this document (page 26) and in chapter 4 because of their importance ⓘ.

The following example gives some more perspective on the multifactorial side by showing that parenting style itself is also a risk factor. The one-sided approach in which the child is the main perpetrator of the problems is also put into perspective:

Example 5: more desirable

> ***"The contemporary view is that disturbed parenting behavior or disrupted parent-child interactions are the result of child temperament and impulsive and oppositional behavior rather than that they cause the behavior in the child. In short, problematic parent-child relationships may maintain or intensify the child's problematic behavior but do not cause these behaviors. However, (…) a number of studies, also show that a deficient parenting style, e.g. lack of responsiveness and overstimulation on the part of the parent, is a risk factor for the development of attention problems and hyperactivity in early childhood."*** [29]

This excerpt gives perspective to the one-sided view that biological causes are the basis of problematic behavior and the environment only perpetuates or intensifies them. As discussed, a strong basis does not stem from brain research because of the small effect sizes. Genetic studies also cannot lead to such a conclusion as the next chapter will discuss.

ⓘ It is quite possible that both brain development and environmental factors explain some of the behavior for some individuals with ADHD, but not all behavior can be explained by these factors.

It is also noteworthy that with respect to environmental factors, it is much easier to find desirable examples than is the case with regard to, for example, brain anatomy. When providing information about ADHD and brain anatomy, too often it is not explicated that a correlation does not immediately mean that "a different brain" is the cause of behavior. In fact, it can also be the other way around, as the aforementioned study in musicians (page 8) shows. In musicians, brain parts associated with finer motor skills are -on the group level- larger on average, which seems to be related to the fact that they frequently use these brain parts.

The foregoing is again summarized in a table:

Table 3: Environmental influences

	Less desirable	More desirable
Correlation is not causation	Suggesting that a relationship with adverse conditions automatically implies causality (ex. 1)	To make clear that correlation does not imply causation (ex. 2, see also chapter 4)
Nature versus Nurture	To suggest that the environment only contributes to an organic disorder that was already present at birth (ex. 3)	Clarifying the interaction between predisposition and environment (ex. 4, 5, see chapter 3)

Chapter 3: ADHD, heredity and the environment

There are many studies available on the heritability of ADHD. The first heritability studies looked at similarities and differences in ADHD characteristics between family members and other relatives. In this area, twin studies in particular are known. Contemporary research focuses on finding the genes that play a role in people with an ADHD classification. These are the well-known “case-control” studies, that study the higher or lower incidence of certain genetic variants in groups with ADHD (the case group) or without (the control group). Both types of research will be explained, starting with twin studies. More and less desirable examples of psycho-educational literature will follow.

Twin studies

Twin/family and adoption studies look at similarities and differences in behaviors between children and adults who are more or less biologically related to each other, such as parents and children, siblings, and so on. If it turns out that people often exhibit the same behaviors within families, it may indicate that heredity plays a role. The tricky thing is that people within a family also live in the same environment so the influence of heredity and environment are not easily separated.

Twin studies in particular are therefore a better method than family studies to estimate the contribution of genetics and environment. The similarities in behavior of identical twin pairs, who are genetically similar, are then compared with the similarities in behavior of fraternal twin pairs, which are genetically similar by about 50% (on average). If identical twins are much more similar than fraternal twins, then genes therefore play an important role, because it is assumed that both identical and fraternal twin pairs have similar environments.

Molecular-genetic studies

The second type of research, molecular-genetic studies, looks directly at particular genetic variants, specifically so-called Single Nucleotide Polymorphisms (SNPs). For the purpose of these guidelines it would take too long to explain exactly genetic variants, but the point is that in the case of ADHD, the genes of -again- groups of people with and without an ADHD classification are compared. If certain genetic variants are relatively more or less prevalent in the different groups, these genetic variants may be involved in the behavior.

The added value of twin studies and molecular genetic studies

Both types of research have provided useful knowledge. For example, twin studies have demonstrated that many character traits such as temperament and (hyper)activity have a substantial hereditary basis. This has implications for the extent to which we can change that temperament, if at all desirable to do so. Certain genetic variants appear to be somewhat more common in ADHD-classified children, although the results are not yet very consistent, and again there is a lot of overlap between the case and the control groups. Thus, the ADHD-related genetic variants also occur, and almost as often, in the control group, and children with an ADHD classification do not necessarily have these genetic variants.

Based on the molecular-genetic research, recent research has combined the genetic variants found and combined their effects into a single genetic risk score. Here, the effect of multiple genetic “risk variants” together in relation to ADHD is viewed. Although the effects are larger than for single genetic variants, this research also shows only small effects. Again, there is a lot of overlap: people with ADHD do necessarily have those genetic variants, and people without ADHD have them almost as often. However, these studies are still in their infancy stage, and the interpretation of the outcomes still needs to be examined more closely.

Interpretation of outcomes and limitations of twin studies

Based on twin studies, it is frequently suggested that a (one) heritability score can be calculated for ADHD as a disorder entity. Regularly, this is then a very exact number as in the following example:

Example 1: Less desirable

Genetic factors play an important role; ADHD tends to run in families and has a heritability rate of 74%.[30]

It is not mentioned here that the estimate is an average between many studies that differ because different populations have different heritability estimates. Displaying a single value of the 'heritability coefficient' suggests that there is one value that applies to ADHD as a (cluster of) behavioral trait(s). However, heritability coefficients describe (behavioral) traits in a given group of people/population at a given time.

Heritability is a complicated concept for many people; an example might clarify what heritability means: In a population in which, for example, problems in the environment such as divorce or poverty play a major role, the contribution of genetic factors may differ from a more optimal environment. This is also the case with ADHD, because ADHD is much more often diagnosed in areas with lower SES (Social Economic Status ⓘ). In areas with lower SES, by definition, poverty is more common and people are more likely to live in disadvantaged neighborhoods. There are also more alcohol abuse, divorce and attachment problems and so on. Therefore, in these situations, environmental factors will strongly contribute to concentration problems, impulsivity and hyperactivity. The influence of heredity may be less than in an environment that gives children more opportunities to develop. In such a more favorable environments their genetic predisposition is also more likely to emerge. This means that that no single heritability score can be calculated, but that the influence of predisposition/environment depends on the group of people studied in heritability research. Because the influence of genetic predisposition can thus vary, it is therefore more desirable to speak of a "range," an interval, of heritability and not a fixed value:

Example 2: more desirable

"According to twin studies, ADHD is among the most heritable disorders with estimates between 60 and 90%". [31]

Expressing heritability as an interval, rather than a fixed and exact number hopefully also has the advantage of raising awareness that heritability studies –similar to studies of brain-anatomy/physiology, etcetera- are also group studies. Twin studies or molecular genetic studies, based on groups, cannot predict the influence of genetics for an individual person. The following example makes this clear.

ⓘ Social Economic Status (SES) is widely used, mostly by social scientists, to see to what extent, for example, variables such as income, education, housing and the like affect other variables such as income in later age, health, and so on.

Example 3: Desirable

"The nature and extent of the contribution made by genetic and environmental factors varies from case to case." [32]

Contrast heritability and environment

What also complicates twin studies is that a given estimate of heritability, such as "50-80%", does not mean that the remaining percentage (20-50%) of the variation of behavior can be explained by the environment. Indeed, the estimate of heritability also include environmental influences woven into the heritability estimate. A high estimate of heritability only means that in a given population, more variation occurs due to heritability. This may also be because the environment is fairly uniform. An example can clarify what heritability estimates mean. Consider, for example, 'reading ability'. If good reading instruction is offered in a population, then any differences in reading ability that remain will be mainly due to heredity. This can result in twin studies showing high heritability while the influence of the environment on overal reading ability is much bigger. But that does not mean that reading education has no effect on the reading skills of children: in fact, it has had its influence by giving hereditary factors more of an opportunity to manifest. Translated to ADHD behavior, high heritability does not mean that environmental factors have (had) little influence as the following statement suggests.

Example 4: Less desirable

"Problems in parenting or parenting styles may make ADHD better or worse, but these do not cause the disorder." [33]

In the next example, it is claimed even more strongly that specific child factors do matter and that parenting would not matter.

Example 5: Less desirable

"Sometimes, you still hear that it is because of parenting that a child is so restless. That is absolutely not true. [...] therefore, ADHD is not a disease, it is not due to parenting. However, ADHD is hereditary. It can, so-called, 'run in the family.'" [34]

Because genetic predisposition and the environment always interact and an ADHD classification is only based on overt behavior (and not, for example, physical factors such as brain activity and brain size et cetera) it cannot be said that the environment alone can improve or worsen the disorder that is already there. After all, both genetic predisposition and the environment have already exerted their influence when a person exhibited the behaviors that are the basis of the ADHD classification. With a favorable environment and good education, children with a predisposition for impulsiveness or busy behavior can learn -although they will certainly not always succeed- to control themselves better so that the (subjective) criteria for an ADHD are no longer met. The following statement makes that it is more difficult to differentiate between genetic predisposition and the environment than is sometimes suggested.

Example 6: Desirable

"Genetic and environmental influences are profoundly intertwined for ADHD and need to be considered jointly." [35]

A very elaborate way of making this clear, is the following example:

Example 7: More desirable
"In contrast to the high heritability estimates, the effects of specific genes are small. When aggregated, they account for only a fraction of variance in symptom expression. How can this gap be explained? First, twin studies, although a potentially powerful tool for dissecting genetic and environmental effects, need to be interpreted with caution for a number of reasons, as they may overestimate genetic main effects (…). For instance, heritability estimates subsume the effects of gene x environment interactions so that subtler environmental effects can be missed.

Second, it remains possible that a large number of genes, some of at least moderate effect, exist but have yet to be identified. The results from linkage studies, if further replicated, provide support for this although genes of major effect are unlikely (…)

Third, genes may interact with each other (…) and with environmental risk factors (…) to increase the risk of ADHD in a non-linear manner so that genes of small main effect have disproportionate power when acting together or with environmental factors." [36]

This example shows how an author can and should express the pitfalls of heritability studies. Additionally, it is important to note that studies of 'gene x environment' interaction and of other genes involved with 'GWAS' -Genome Wide Association Studies-, have not yet produced results that can explain much of the behavior. The effects found are often small. No genes with an average effect have been found either: only genetic variants with small effects have been found.ⓘ

Molecular genetic studies
In the previous example, the strong effects of twin studies are contrasted to the low effects shown by molecular genetic studies. Thus, the genetic variants found seem to explain very little of the behavior. The contrast discussed by the authors provides an opportunity to highlight limitations of twin studies and explain so-called 'interaction effects' between genetic predisposition and the environment. In textbooks, this 'gene x environment' interaction is not often highlighted and it may be the same in other forms of education.37 Explicitly mentioning 'phantom heredity' or the 'problem of missing heredity', as this phenomenon is known, occurs even less.

Previously found gene variations were based on candidate gene studies. In these studies, certain gene variations were examined that were 'candidates' to display an effect. For example, they were selected because they were related to the brain or to dopamine. As yet, the outcomes of these studies are not reproduced in genome-wide studies. This means that the outcomes of these candidate gene studies were most likely the result of findings by chance due to the use of research samples that were too small. Combined with publication bias -positive findings are published more often- this has led to the fact that these 'false positive' findings in meta-analyses have not been filtered out. After all, if positive findings are published more often, those effects will also be found in meta-studies because studies that shows no effect are not included in meta-analyses. Therefore, it is important to stop relying on (metanalyses of) candidate gene studies and look at genome wide studies instead, provided they have been conducted with large research samples.

However, by not discussing this contrast, the false impression may arise that children with an ADHD classification have genetic variants that 'normal' children do not have, as in the following example.

Example 8: Less desirable

> ***"From twin, adoption and family studies, genetic influences are known to play an important role in the etiology of ADHD; the disorder might be determined for about 60 - 80% by genetic factors. The risk of ADHD in brothers and sisters of a child with ADHD appears to be about three times greater than in the general population (Biederman, 2005). Furthermore, clear indications have been found for the involvement of genes that influence the dopaminergic systems (DRD4, DRD5, dat-1). So-called 'genomewide linkage studies' have shown possible ADHD-associated regions on chromosomes 16pi3, i5q, 9q and yp and i7pn."*** [38]

First of all, the 'involvement' of the gene variations discussed is insufficiently specified in this excerpt. After all, the effect sizes are small and again, there is much overlap: many people with ADHD don't have these gene variations, and the gene variations are almost as common in the control groups with people without ADHD. The following excerpt clearly explains the small influence of genetic and other influences:

Example 9: Desirable

> ***"Finally, it is emphasized that the (…) etiological factors each make only a small contribution to the development of ADHD. It is the combination of various genetic and environmental factors that increases the risk of developing ADHD. In addition, there are different combinations of factors and different developmental pathways that can ultimately lead to ADHD."*** [39]

It is important to emphasize again that most genetic variations that were found in candidate gene studies were not found as a possible risk factor in Genome Wide Association Studies. These GWAS did find other genetic variations, but even these can only explain little of the behavior. "Normal" kids have these genetic variants almost as often in relative terms, and even more often in absolute terms (because the group of children without ADHD classification is larger). Many children with an ADHD-classification do not show the genetic variants associated with ADHD. The genetic variants concerned are thus – just as with neuro-anatomical/-physiological or –chemical attributes, not a "necessary or sufficient condition".

Table 4: Basic ingredients for proper explanation of genetics

	Less desirable	More desirable
Heritability as a fluctuating estimate of the contribution of genetic factors to a trait or set of behaviors in a certain population at a certain time and not as a fixed value belonging to a disorder.	A specific value as if ADHD has one value of genetic influence that is the same for each population and each individual (ex. 1)	A range of heritability from different studies (ex. 2, 3)
Difference between effect size of twin studies vs. molecular genetic studies and possible explanations	Only the large effects of twin studies, in combination with 'involved genetic variants' without reporting low (e.g. 8) effect sizes	Effect sizes of both twins and molecular genetic studies, and reflect on discrepancies (ex. 7)
Interaction of genetic and environmental influences	That environment alone contributes to the pre-existing disorder (e.g. 4.5)	That genes and environment interact leading to the disruptive behavior (e.g. 6, 7,9)

Chapter 4: Problems in the interpretation of ADHD-research

This chapter addresses some of the problems with properly discussing and interpreting of ADHD-related research, which are important for adequately communicating about ADHD. Some of these issues have already been touched upon in other chapters of these guidelines, but are discussed here in more detail.

Correlation and causation

ADHD has been associated with several environmental as well as personal predisposing factors. These factors often interact, making causal pathways difficult to identify and variable from one person to the next. Attention problems, restlessness and impulsivity can themselves be a root cause of problems at school and in later life, but underlying adverse environmental circumstances may also directly or indirectly cause an unfavorable development in life. In psycho-educational literature and other communication, sufficient attention must therefore be paid to the complexity of all these interacting risk factors together. Often, attentional problems, hyperactivity and impulsiveness are mentioned as risk factors, but the underlying relations of these behaviors with other factors, and possible confounders, are often left unmentioned. The following example illustrates this point well.

Example 1: Less desirable.

> ***"Several longitudinal studies leave no doubt that this disorder puts children at risk for problems in adolescence. This includes poor school performance, reading problems, internalizing problems, conduct disorder, anti-social behavior, drug use or abuse, social problems, accidents, symptoms of eating disorders and teenage pregnancy."*** [40]

Longitudinal studies are studies that look at long-term relationships between several factors. The section cited above suggests that ADHD is at the root of a variety of problems later in life. However, these problems may interact in various ways that are left unmentioned. For example, reading problems may contribute to internalizing problems and poor school performance; social problems can contribute to the development of substance abuse and antisocial behavior, and so on. Moreover, in many cases, underlying social problems, such as poverty, discrimination, divorce and neglect are present, which are also associated with and can contribute to development of hyperactive behavior and attentional problems. Importantly: ADHD does not explain any of the behavioral problems, but only gives a name to these problems. With regard to smoking during pregnancy - as undesirable and harmful as this is, for example, doubt has been cast on the causal link with ADHD because parents who smoke often also have a lower SES (Social Economic Status). In addition, parents who themselves are classified with ADHD are more likely to smoke cigarettes ⓘ. As such, the association between smoking during pregnancy and ADHD is not as clear cut as it is often represented. The following excerpt reflects this complexity.

ⓘ This is an example of gene – environment correlation.

Example 2: Desirable

"According to some brain researchers, including Dick Swaab, children are much more likely to develop ADHD when the mother smokes during pregnancy. However, this does not necessarily imply a cause-and-effect relationship, but denotes an observed a statistical correlation.[41]

Circular reasoning and tautologies

Several scholars have warned about confusing "naming & explaining", such as the former president of the 4th edition of the DSM, the psychiatric diagnostic manual. The ADHD classification is no exception: when we classify attentional problems, hyperactive and impulsive behavior as ADHD, we have not yet explained any of these behaviors. The following example shows how the suggestion is made that ADHD causes the behaviors it merely describes, with the authors leaning towards circular reasoning:

Example 3: Less desirable

"ADHD affects not only a child's ability to pay attention or sit still at school, it also affects relationships with family and other children." [42]

The ADHD definition consists of several criteria pertaining to psychological/social dysfunction in education (or in relation to work). Children would not receive an ADHD classification if we did not deem their behavior in educational settings and in contact with others as problematic. ADHD does not cause these problems, but names them; after all causes and motives for the behavior can vary. The following statement is another example of circular reasoning:

Example 4: Less desirable

"ADHD is an explanation of behaviors, not an excuse for them." [43]

To prevent naming and explaining from being confused and becoming apt to circular reasoning, it can be helpful to name existing problems as clearly as possible and to clarify how the causal paths can run in different ways, such as in the following example:

Example 5: More desirable

"Concentration problems, impulsivity and hyperactivity can have different and mutually interfering causes and these behaviors can by themselves also contribute to problems in education or in a work situation. However, using the term ADHD to indicate the presence of these problems does not explain them." [44]

The course of ADHD

Research findings vary on the course of ADHD. According to some estimates, the majority of those with an ADHD classification no longer meet the criteria later in life, while according to other studies, it is a minority. It is not for this guideline to make a final judgment on which research outcome is the most valid. Moreover, the differences also depend on the definition. Is it about being symptom-free? Or is it about a change in behavior such that one can no longer speak of ADHD according to the definition? In both cases, however, it is important to avoid "determinism" and generalization. To suggest that children with an ADHD classification always grow out of the problems is contrary to research outcomes, but to suggest that ADHD is lifelong is incorrect, potentially stigmatizing and burdensome for children. In addition, research also shows that lower expectations of the environment can actually result in lower performance; we call that a "self-fulfilling prophecy," or a "self-affirming prediction. The following examples are therefore less desirable:

Example 6: Less desirable

"A person does not 'grow out of'ADHD." [45]

Example 7: Less desirable

"ADHD is a lifelong brain disorder." [46]

It is more desirable to make it clear that there are individual differences regarding the course of problems as in the following example.

Example 8: more preferable

"Attention problems are more persistent than hyperactivity and impulsivity. In children with more severe problems these problems tend to be more persevering than in children with less severe problems, but it is not the case that children with more severe problems by definition do not grow over them and children with milder problems do." [47]

Table 5: various problems with the interpretation research data

	Less desirable	More desirable
Correlation and causality	On correlation and causation of ADHD as a risk factor without naming possible underlying connections (ex. 1)	Underlying connections and/or to warn against correlation-causality confusion (ex. 2)
To confuse naming and explaining	ADHD, a term for social problems and issues in e.g. educational situations as an explanation for those problems (ex. 3,4)	Against the confusing of naming and explaining (ex. 5)
Prognosis	That ADHD symptoms are always permanent (ex. 6, 7)	Making it clear that the course may vary, depending the severity of symptomps and many other variables (ex. 8)

Chapter 5: Decisions when providing information: wording and selection of topics

These guidelines mainly discuss the interpretation of research findings and ways to write about these as clearly as possible. By doing so, stigmatization and a suction effect of classifications can possibly be prevented; for example, by avoiding telling children they are medical 'ill' based solely on their behavior. Also the decisions that are made when providing information are important: which topics do I discuss, or not? And which words should I use in the information and which should I avoid? Specific selections of topics can also create an incorrect or one-sided picture of ADHD, and specific decisions in wording can also contribute to this one-sidedness.

Wording

Wording is not so much about inaccuracies, but certain language can contribute to stigmatization and to a one-sided, mostly medical view of ADHD behavior. The following recommendations are therefore suggested for authors writing about ADHD.

Neurodevelopmental?

The DSM 5 has categorized ADHD as a neurodevelopmental disorder. Although the authors of the DSM themselves do not state that neurodevelopment refers to slower or problematic brain development, we fear that 'neurodevelopmental' might easily be understood as such and we advise not to use it to avoid confusion. For example, Wikipedia explains neurodevelopmental as: 'disorders that affect the development of the nervous system'6. Classifications such as ADHD have helped structure our research into behaviors -and this was exactly what the 'valuable heuristic constructs' of the DSM intended to do48. However, the outcome that ADHD has a correlation with brain development was merely one of many associations and as we have discussed extensively in these guidelines:

1. The effect sizes that are found are small: the neurobiology of an individual child with an ADHD classification does not necessarily differ from a child without an ADHD classification as there is much overlap between those with and without an ADHD classification.

2. Differences like slower brain development are not necessarily permanent and in general differences do not necessarily imply disorder.

3. ADHD also correlates with many environmental factors and correlation does not imply causality.

Disease/Illness/disorder

There are no biological tests for ADHD. It is not visible in the brains or genes of individuals and there are no other physical characteristics which are directly linked to ADHD (with the exception of children with rare genetic disorders, in whom ADHD behavior is part of multiple developmental problems). The classification is solely based on broadly defined behavioral criteria, behaviors that many children and adults display to a greater or lesser extent. These criteria depend on social norms: as the DSM-IV recognizes, for example, it is often very hard to distinguish disorders from other disorders, or from no disorder at all. It is therefore considered unnecessarily stigmatizing and undesirable to speak of a disease or illness. Some experts are advocating to refrain from 'disorder' as well and speak only of "attention deficit and hyperactivity". The authors of these guidelines take no definite stance in relation to the use of 'disorder' although we advocate against the use of 'disease' and 'illness'. [49]

Symptom versus Criterion

The behavioral characteristics of the disorders defined in the DSM are often referred to as 'symptoms', although the DSM also used the term 'criteria'. The problem with 'symptom' is the meaning; according to the Merriam Webster dictionary[50]: 'subjective evidence of disease or physical disturbance'. In the case of ADHD, however, the behavioral criteria do not provide evidence for a disease or physical disturbance. The behaviors themselves, if they occur in combination and to a severe degree, are the problem. There can certainly be underlying causes, but ADHD is not the cause that is recognized, but the name for the combination of problems. Unlike, for example, fever, blood in the stool, skin rash or weight loss, the criteria for ADHD cannot be determined objectively. Compared with 'symptom', a word like 'criterion' does more justice to the subjective aspect and the decision-making process that is necessary to speak of ADHD.

Diagnosis

The DSM is a system of classification that can promote communication between care providers and facilitate research. ADHD can therefore best be described as a classification from the DSM. However, ADHD is also regularly referred to as a 'diagnosis'. According to the Oxford Learner's diary[51], a diagnosis is 'the act of discovering or identifying the exact cause of an illness or a problem'. However, because no singular cause is identified with ADHD, and the word illness is problematic, we suggest to describe ADHD as a (behavioral) classification. An additional reason is that in mental health care diagnosis often refers to a more extensive description of the problem analysis that does look at possible causes of or motives for behavior. By clearly separating the classification from the search for causes, we hope to prevent confusion of tongues and we also hope to prevent ADHD from being perceived as the cause of the problems.

Patient versus client

The term 'patient' is sometimes also used when it comes to children or adults with an ADHD classification. According to the Merriam Webster dictionary[52] this refers to medical care and treatment. As these guidelines argue, biological attributes are by no means necessary or sufficient and are not the basis of an ADHD classification. Merriam Webster definition also defines patient as 'one that is acted upon'. These guidelines follow the Dutch guidelines of ADHD care that point to safeguarding the autonomy and self-esteem of people with an ADHD classification which is at stake in light of the foregoing. On the other hand, the word 'client', also used often has a connotation associated with care as a product and people as consumers. These guideline cannot provide definitive answers or advice, especially in this matter. However, it may be a good solution to avoid collective terms such as patient/client, person with ADHD, etcetera, but rather refer to persons who experience certain problems, and to be as descriptive as possible, for example by referring to someone who has feelings of restlessness or has trouble focusing while performing certain activities.

Choice of topic

Choice of topics can also greatly contribute to confusion and a one-sided view of ADHD. Writing only or mainly about biological research or mainly about environmental influences and society can create an imbalance in the provision of information. We discuss a number of important topics that do not always receive the attention they deserve in information about ADHD.

Societal influences

Chapter 3 already discussed some examples in which the influence of the direct environment, such as the family, was strongly downplayed, while the influence of, for example, genetics, was emphasized. With regard to the societal environment, this is regularly lacking in information on ADHD. Nevertheless, in 2014 and 2017, the Dutch Health Council[53] wrote about the importance of society and the environment in relation to ADHD. In 2014, the Health Council described a number of societal factors that may be related to ADHD, such as:

- changing family situations due to changes in family size, shape and forms of cohabitation
- changing forms of childcare due to changes in parents' work patterns and financing of childcare
- changing parenting styles due to changes in pedagogical insights
- changes in media due to the rise of the internet and mobile media
- changes in education due to changes in teacher education and emphasis on specific skills in children.

The report states that it is difficult to establish this societal influence empirically, but some mechanisms of action are nevertheless quite convincing. As an example, the report shows the influence of diagnosis-treatment combinations (DBCs), in which insurance companies only reimburse mental health care in the case of a DSM classification. This introduced an incentive to classify behavior according to the DSM because this classification was a condition for financial support and care. Currently in the Netherlands, however, mental healthcare without a DSM classification is becoming increasingly common.

Birth month studies

Research indicates that there are strong 'systemic incentives' in healthcare and education that have contributed to the increase in ADHD classifications[54]. For example, birth month studies have shown that early learners are more likely than late learners to be classified as ADHD. These associations have been found in various countries. The effect sizes were considerable, with youngest in class being 20 and 80% more likely to receive an ADHD classification, and outliers of over 150% increase and 2 studies in Denmark finding no effect[54]. It should be noted that other influences than early/late school attendance could in theory also contribute to this association.

Given the considerable effect size, and the fact that it is very easy for care providers to check whether relatively young age plays a role, the inclusion of information about these birth month studies in information is considered highly desirable.

Should ADHD still be used in practice?

The taskforce acknowledges that there are individuals who are more active, more impulsive and who have more difficulties than others when focusing on tasks, in particular if they do not find these interesting. These behaviors can primarily be related to circumstances or societal demands but can also be mainly related to a person's disposition. We also agree that some of these people may benefit from professional psycho-social interventions and/or (preferably temporary) treatment with psycho-stimulants. Additionally, we agree that research based on the ADHD construct has provided useful insights into the possible benefits of such interventions and origins of e.g. differences in disposition between children. However, the authors of these guidelines hold differing views on whether and when an ADHD classification should be used in practice.

On the one side there are those who are more inclined to use an ADHD classification as a starting point. They do so mainly because they believe this does most justice to, and takes most advantage of, the research that has been done and -for example- guidelines that have thus far been developed. On the other side -although these views and their proponents can be placed on a continuum- some members of the taskforce believe that an ADHD classification should be the last resort. They aim to avoid individualized psychological/ psychiatric 'treatment' for issues that are often rooted in, or related to, the social context of the child such as overburdened parents, teachers in overcrowded classrooms or society's difficulty in dealing with temperamental children.
However, regardless of our position on the continuum outlined above, all of us believe that the widespread misinformation on ADHD -often projected as a brain-based disorder rather than a descriptive classification- should be kept away from children in particular. Additionally, all of us believe that for the ADHD construct to remain useful in any way, a very serious effort is needed to improve our discourse on ADHD. These guidelines are a starting point for doing so.

Table 6: choices when making information: subject and choice of words

	Les desirable	**More desirable**
Wording	Excessive use of medical jargon	avoid medical jargon and use normalizing language as much as possible
Societal influences	Omitting the influence of norms and society	Mention of societal influence, in particular of month of birth studies

Further reading

For those who are interested in the discourse on ADHD this is a brief selection of articles that are related to this.

Batstra, L., Foget, L., van Haeringen, C., Te Meerman, S., & Thoutenhoofd, E. D. (2020). What children and young people learn about ADHD from youth information books: A text analysis of nine books on ADHD available in Dutch. Scandinavian journal of child and adolescent psychiatry and psychology.

Bourdaa, M., Konsman, J. P., Sécail, C., Venturini, T., Veyrat-Masson, I., & Gonon, F. (2015). Does television reflect the evolution of scientific knowledge? The case of attention deficit hyperactivity disorder coverage on French television. Public Understanding of Science, 24(2), 200-209.

Danforth, S., & Kim, T. (2008). Tracing the metaphors of ADHD: A preliminary analysis with implications for inclusive education. International Journal of Inclusive Education, 12(1), 49-64.

Erlandsson, S., Lundin, L., & Punzi, E. (2016). A discursive analysis concerning information on “ADHD” presented to parents by the National Institute of Mental Health (USA). International Journal of Qualitative Studies on Health and Well-Being, 11(1), 30938.

Freedman, J. E., & Honkasilta, J. M. (2017). Dictating the boundaries of ab/normality: a critical discourse analysis of the diagnostic criteria for attention deficit hyperactivity disorder and hyperkinetic disorder. Disability & Society, 32(4), 565-588.

Freedman, J. E. (2016). An analysis of the discourses on attention deficit hyperactivity disorder (ADHD) in US special education textbooks, with implications for inclusive education. International Journal of Inclusive Education, 20(1), 32-51.

Horton-Salway, M. (2011). Repertoires of ADHD in UK newspaper media. Health:, 15(5), 533-549.

van Langen, M. J., Szőke, R., Rijkelijkhuizen, D. N., Durston, S., & van Hulst, B. M. (2022). Lost in explanation: internal conflicts in the discourse of ADHD psychoeducation. BMC psychiatry, 22(1), 1-9.

te Meerman, S., Batstra, L., Hoekstra, R., & Grietens, H. (2017). Academic textbooks on ADHD genetics: balanced or biased?. International journal of qualitative studies on health and well-Being, 12(sup1), 1305590.

te Meerman, S., Freedman, J.E., Batstra, L. (2022). ADHD and reification: Four ways a psychiatric construct is portrayed as a disease. Frontiers in Psychiatry, Sec. Public Mental Health https://doi.org/10.3389/fpsyt.2022.1055328

te Meerman, S., Batstra, L., Freedman, J. E., Hoekstra, R., & Grietens, H. (2020). ADHD and brain anatomy: What do academic textbooks used in the Netherlands tell students?. Children & society, 34(2), 136-150.

Ponnou, S., & Gonon, F. (2017). How French media have portrayed ADHD to the lay public and to social workers. International journal of qualitative studies on health and well-being, 12(sup1), 1298244.

Appendix A: Participants and background

These guidelines were created by the Taskforce on psychoeducational literature, coordinated by Sanne te Meerman (sociologist, Druk & Dwars). The taskforce is part of the Academic Workshop on ADHD and unruly behavior and held its first meeting in July 2018. Since then, work on these guidelines has been done through phone conferences, (online) meetings and email. With several discussion papers, participants have provided substantive feedback on desirable and less desirable examples related to education. The participants of this working group are (in alphabetical order):

Laura Batstra (Druk & Dwars, Professor Child & Family Welfare, University of Groningen)
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David Con (Psychiatrist, private practice).
Tycho Dekkers (Senior Researcher/GZ-psychologist, Accare/Levvel)
Jeannette Doornenbal† (lector Youth, Education & Society, Hanze University of Applied Sciences)
Justin E. Freedman (Assistant Professor, Rowan University)
Annabeth Groenman (Senior Researcher, Accare)
Pieter Hoekstra (Professor Child & Adolescent psychiatry, University Medical Center Groningen).
Maya Hofhuis-van den Brink (Pedagogue, KOOS Utrecht)
Rudi Hofstede (Youth policy, Heerenveen)
Elin Hondebrink (Druk & Dwars, Lay-out and website, University of Groningen).
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Appendix B: ADHD and the DSM

What is ADHD?

These guidelines are based on the definition of ADHD as defined in the DSM-5[55] and (the Dutch version of these guidelines) the Dutch ADHD care standard. In this standard, ADHD is referred to as an extreme on the continuum from concentrated, calm and controlled behavior to unconcentrated and/or busy and impulsive behavior.

Definition and criteria

In DSM 5, in order to speak of ADHD, a person must meet 6 out of 9 behavioral criteria for:
1. **Inattention** and 2. **Hyperactivity/impulsivity**.

The criteria for **inattention** include behavioral criteria like:
a. Often fails to give close attention to details or makes careless mistakes in e.g. schoolwork.
b. Often has difficulty sustaining attention in tasks or play activities.
c. Often does not seem to listen when spoken to directly.

The criteria for **hyperactivity/impulsivity** include behavioral criteria like
a. Often fidgets with or taps hands or feet or squirms in seat.
b. Often leaves seat in situations when remaining seated is expected
c. Often runs about or climbs in situations where it is inappropriate

Furthermore, there are several criteria that must be met in addition to these.
• The behavioral criteria must be present for at least 6 months.
• Several inattentive or hyperactive-impulsive criteria are met in two or more settings like home or school.
• There is clear evidence that the behaviors interfere with, or reduce the quality of, social, academic, or occupational functioning.

The DSM also makes a distinction between 3 types of “presentations” of ADHD:
The **Combined presentation**: if 6 out of 9 behavioral criteria are met for inattention as well as hyperactivity/impulsivity.
The **Predominantly inattentive presentation**: if 6 out of 9 behavioral criteria are met for inattention but not for hyperactivity/impulsivity
The Predominantly hyperactive/impulsive presentation: if 6 out of 9 behavioral criteria are met for hyperactivity/impulsivity but not for inattention.

The DSM also specifies severity as follows:
Mild: Few, if any, criteria in excess of those required to make the diagnosis are present.
Moderate: criteria are met or functional impairment between “mild” and “severe” is present.
Severe: Many criteria in excess of those required to make the diagnosis are present.

Please note that this overview gives only an impression of the DSM section on ADHD. Always refer to the DSM-5 for exact specifications (page 59 – 62).

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